

# RARE FOUNDATION ALLIANCE



GLOBALGENES.ORG

## RARE Foundation Alliance Members

Global Genes RARE Foundation Alliance is made up of over 500 disease foundations that have committed to collaborating with Global Genes and other nonprofit foundations in order to create a stronger, collective voice in the rare disease community.

[#11q Research & Resource Group](#) – Jacobsen Syndrome, 11q Chromosome

[1p36 Deletion Support & Awareness](#) – 1p36 Deletion Syndrome

[4p- Support Group](#) – Wolf-Hirschhorn Syndrome and related 4p conditions

[5p-Society](#)– 5p- Syndrome, Cat Cry Syndrome, Cri du Chat Syndrome

[A Foundation Building Strength for Nemaline Myopathy](#) – Nemaline Myopathy

[A Nonprofit Group Enriching Lives \(ANGEL AID\)](#) - Multiple rare diseases

[Aaron's Ohtahara](#) – Ohtahara Syndrome

[Aarskog Foundation](#)– Aarskog-Scott Syndrome

[Acid Maltase Deficiency Association](#)– Acid Maltase Deficiency, Pompe's Disease

[Acromegaly Community](#) – Acromegaly and Gigantism

[Acoustic Neuroma Association](#) – Acoustic Neuroma

[ADCY5.org](#) – ADCY5 Mutation

[Addi & Cassi Fund](#) – Niemann Pick Type C

[ADNPkids](#) – ADNP Syndrome, Helsmoortal\_Van Der AA Syndrome

[Adrenal Insufficiency United](#) – Adrenal Insufficiency

[Adult Polyglucosan Body Disease Research Foundation](#) (APBDRF) – APBD

[Advancing Sickle Cell Advocacy Project, Inc.](#) – Sickle Cell Disease

[Advocacy & Awareness for Immune Disorders Association](#) – Primary Immunodeficiency Diseases (PID), Hereditary Angioedema, Pediatric Acute onset Neuropsychiatric Syndrome (PANS), Autoimmune diseases

[AHC Federation of Europe](#) – Alternating Hemiplegia of Childhood

[Aicardi-Goutieres Syndrome Association of the Americas](#) (AGSAA)- Aicardi-Goutieres Syndrome

[Aidan Jack Seeger Foundation](#) – Adrenoleukodystrophy

[AKU Society](#) – Alkaptonuria

[AKU Society North America](#) – Alkaptonuria

[Alagille Syndrome Alliance](#) – Alagille Syndrome

[Alect2 Alliance](#) – Amyloidosis Alect2

[ALD Connect](#) – Adrenoleukodystrophy

[All Things Kabuki](#) – Kabuki Syndrome

[Alliance for Cryoglobulinemia](#) – Cryoglobulinemia

[Alliance for Safety Awareness for Patients](#) – Hospital-Acquired Necrotizing Fasciitis

[Alpha-1 Foundation](#) – Alpha-1 Antitrypsin Deficiency

[Alport Syndrome Foundation](#) – Alport Syndrome

[Alström Angels](#) – Alström Syndrome

[Alström Syndrome International](#) – Alström Syndrome

[Alternating Hemiplegia of Childhood Foundation](#) – Alternating Hemiplegia of Childhood

[AMENSupport](#) – Multiple Endocrine Neoplasia

[American Behcet's Disease Association](#) – Behcet's Disease

[American Partnership for Eosinophilic Disorders](#) – Eosinophilic Disorders

[American Prophyria Foundation](#) – Prophyria Disease

[Amour Fund of Alpha Epsilon Omega Foundation](#) – Congenital Disorders of Glycosylation (CDG)

[Amyloidosis Foundation, Inc.](#) – Amyloidosis

[Amyloidosis Research Consortium](#) – Amyloidosis

[Angelman Biomarkers and Outcome Measures Alliance](#) (A-BOM)

[Angels with Missing Pieces](#) – 22Q Deletion Syndrome

[Angioma Alliance](#) – Cavernous Angioma

[Appendix Cancer / Pseudomyxoma Peritonei Research Foundation](#)

[\(ACPMP\)](#)– Pseudomyxoma Peritonei

[Aplastic Anemia and MDS International Foundation](#) – Aplastic anemia, Myelodysplastic syndromes, Paroxysmal nocturnal hemoglobinuria

[APS Type 1 Foundation](#) – APS Type 1 (APECED)

[Arachnoiditis Society for Awareness and Prevention](#) – Arachnoiditis

[Arachnoiditis and Chronic Meningitis Collaborative Research Network](#)

[Asociación Española De Amiloidosis](#) - Amyloidosis

[Association for Creatine Deficiencies](#) – Creatine Transport Deficiency, Guanidinoacetate Methyltransferase Deficiency, L-Arginine: Glycine Amidinotransferase

[Association for Glycogen Storage Disease](#) – Glycogen Storage Disease

[Association of Peyronie’s Disease Advocates](#) – Peyronie’s disease

[AT Children’s Project](#) – Ataxia-Telangiectasia

[Atacsia a Fi – Ataxia and Me](#) – Ataxia

[Atlanta S.C.A.R., Inc](#) – Sickle Cell Disease

[A Twist of Fate](#) – Arterial tortuosity syndrome

[Atypical HUS Foundation](#) – Atypical Hemolytic Uremic Syndrome

[Autoimmune Hepatitis Association](#) – Autoimmune Hepatitis

[Autoinflammatory Alliance](#) – Cryopyrin-Associated Periodic Syndromes, Neonatal-Onset Multisystem Inflammatory Disease, Chronic Infantile Neurological Cutaneous and Articular Syndrome, Familial Cold Autoinflammatory Syndrome

[Aux Pas Du Coeur](#) – GNE Myopathy, Duchenne Muscular Dystrophy

[Avery’s Angels Gastroschisis Foundation](#) – Gastroschisis Disease

[Avery’s Hope](#)– GI Diseases

[Aware of Angels](#) – Multiple Rare Diseases

[AXYS](#) – One or more extra X and/or Y chromosomes

[Bardet Biedl Australia](#) – Bardet-Biedl Syndrome

[Barth Syndrome Foundation](#) – Barth Syndrome

[Bcureful](#) – Tuberous Sclerosis Complex

[Beautiful You MRKH Foundation](#) – Mayer-Rokitansky-Küster-Hauser Syndrome

[Beckwith-Wiedemann Children's Foundation International](#) - Beckwith-Wiedemann Syndrome

[Ben's Dream](#) – Sanfilippo Syndrome

[Ben's Friends](#) – All Rare Diseases

[Bethany's Hope Foundation](#)

[Beyond Batten Disease Foundation](#) – Batten Disease

[BlackSwan Foundation](#) – Multiple Rare Diseases, Switzerland

[Bohring-Opitz Syndrome Foundation, Inc.](#) – Bohring-Opitz Syndrome

[Bold Lips For Sickle Cell](#) – Sickle Cell Disease

[Boomer Esiason Foundation](#) – Cystic Fibrosis

[Born a Hero](#) – Pfeiffer Syndrome

[BPAN Warriors](#)– Beta-Propeller Protein-Associated Neurodegeneration

[BRBN Alliance](#) – Blue Rubber Bleb Nevus

[Bridge the Gap](#) – SYNGAP1

[Bronchiectasis Foundation](#) – Bronchiectasis

[CADASIL Together We Have Hope](#) – Cerebral Autosomal Dominant Arteriopathy  
Subcortical Infarcts Leukoencephalopathy

[California Action Link for Rare Diseases Inc. \(CAL RARE\)](#) – All Rare Diseases

[Care Beyond Diagnosis](#) – Multiple Rare Diseases

[Cailee's Corner](#) – Familia Exudative Vitreopathy (FEVR)

[Campbell Burns Metabolic Trust](#) – Metabolic Disorders

[Canadian Association of Pompe](#) – Pompe Disease

[Canadian Fabry Association](#) – Fabry Disease

[Canadian Marfan Association](#) – Marfan Syndrome, Loeys-Dietz Syndrome, ACTA2,  
Familial Aortic Aneurysm, Familial Ectopia Lentis disorders

[Canadian MPS Society](#)-Mucopolysaccharide and Related Diseases

[Canadian Organization for Rare Disorders](#) – Multiple Rare Diseases

[Canadian PKU & Allied Disorders](#) – Phenylketonuria

[CARES Foundation](#) – Congenital Adrenal Hyperplasia

[Caring Voice Coalition](#) – Multiple Rare Diseases

[Carion Fenn Foundation](#) – Syringomyelia, Arnold Chiari Malformatio

[Castleman Disease Collaborative Network](#) – Castleman Disease

[CCHS Family Network /CCHS Foundation](#) – Congenital Central Hypoventilation  
Syndrome

[CDG Care](#) – Congenital disorders of glycosylation

[CDKL5 Canada](#)

[CDKL5 Research Collaborative](#)

[Center for Chronic Illness](#)

[Central California Hemophilia Foundation](#) – Inherited Bleeding Disorders

[CFC International](#) – Cardio-Facio-Cutaneous Syndrome

[CHAMP1ResearchFoundation](#) – CHAMP1

[Champions Action Network](#)

[Chasing Life Project](#) – Multiple Rare Diseases

[Cheyanna's Champions 4 Children \(CC4C\)](#) – Multiple Rare Diseases & Undiagnosed

[chILD Foundation](#) – Interstitial Lung Disease

[Child Neurology Foundation](#) – Childhood Neurologic Disorders

[Children's Alopecia Project](#) – Alopecia

[Children's Cardiomyopathy Foundation](#) – Pediatric Cardiomyopathy

[Children's Cerebral Palsy Movement](#) – Multiple Rare Diseases

[Children's Craniofacial Association](#) – Craniofacial Disorders

[Children's Gaucher Research Foundation](#) – Gaucher Disease Types 2/3

[Children's Tumor Foundation](#) – Neurofibromatosis Disease

[Chinese Organization for Rare Disorders](#) – Multiple Rare Diseases

[Chion Foundation](#) – Prader-Willi Syndrome

[Chive Charities](#) – Multiple Rare Diseases

[Cholangiocarcinoma Foundation](#)

[Chordoma Foundation](#) – Chordoma, Sarcoma

[Choroideremia Research Foundation](#) – Choroideremia

[Chronic Intractable Pain And You Sites, Inc.](#) – Chronic and/or Intractable Pain

[Chronic Pain Partners](#)

[CIDP Will Not Win](#) – Chronic inflammatory demyelinating polyneuropathy (CIDP)

[Cincinnati Comprehensive Sickle Cell Center at Cincinnati Children's Hospital](#) –  
Sickle Cell Disease

[Citizens United for Research in Epilepsy](#) – Epilepsy

[CLOVES Syndrome Community](#) – CLOVES Syndrome

[CMTC-OVM US](#) – CMTC (Van Lohuizen Syndrome)

[Coalition Duchenne](#) – Duchenne Muscular Dystrophy

[Complex Child E-Magazine](#) – Multiple Pediatric Rare Diseases

[Congenital Hyperinsulinism International](#) – Congenital Hyperinsulinism

[Connecting Families Urea Cycle Disorders Foundation](#)

[Coriell Institute for Medical Research](#) – Multiple Rare Diseases

[Cornelia de Lange Syndrome Foundation](#) – Cornelia de Lange Syndrome

[Cortical Foundation](#) – Cortical Malformations

[Costello Syndrome Family Network](#) – Costello Syndrome

[Courageous Faces Foundation](#) - Multiple Rare Diseases

[CRMO Foundation](#) - Chronic Recurrent Multifocal Osteomyelitis

[Crohn's Disease Warrior Patrol](#) – Crohn's Disease, Ulcerative Colitis

[CPRS Forum](#)– Complex Regional Pain Syndrome

[CSNK2A1 Foundation](#)– Okur-Chung Neurodevelopmental Syndrome (OCNDS)

[Cure CADASIL](#)-CADASIL

[Cure CMD](#) – Congenital Muscular Dystrophy

[Cure CMT4j/ Talia Duff Foundation](#)– Charcot Marie Tooth Disease, Type 4j (CMT4j)

[Cure Duchenne](#) – Duchenne Muscular Dystrophy

[Cure GM1 Foundation](#) – GM1 Gangliosidosis

[Cure HHT](#) – Hereditary Hemorrhagic Telangiectasia

[Cure JM Foundation](#) – Juvenile Myositis, Juvenile Dermatomyositis, Amyopathic Dermatomyositis and Juvenile Polymyositis

[CureLGMD2j Foundation](#)– Limb Girdle Muscular Dystrophy Type 2

[Cure RTD Foundation](#)– Riboflavin Transporter Deficiency Neuropathy

[Cure Sanfilippo Foundation](#) – Sanfilippo Syndrome

[Cure SMA](#) - Spinal Muscular Atrophy

[Cure Surf1](#) – SURF1 Leigh Syndrome

[Cure TBM](#)– TracheoBronchoMalacia

[Cures Within Reach](#) – Multiple Rare Diseases

[Cure VCP Disease](#)

[Curing Retinal Blindness Foundation](#) – Leber's Congenital Amaurosis, Retinitis Pigmentosa

[Cushing's Support and Research Foundation](#) – Cushing's Syndrome

[Cutaneous Lymphoma Foundation](#) – Cutaneous Lymphoma Disease  
[Cyclic Vomiting Syndrome Association](#) – Cyclic Vomiting Syndrome  
[Cystic Fibrosis Relief Fund](#) - Cystic Fibrosis  
[Cystic Fibrosis Reproductive and Sexual Health Collaborative](#) – Cystic Fibrosis  
[Cystic Fibrosis Research, Inc.](#) – Cystic Fibrosis  
[Cystinosis Research Network](#) – Cystinosis  
[Dana’s Angels Research Trust](#) – Niemann Pick Type C  
[Danny’s Dose Alliance](#) – Rare Diseases, Chronic Illness  
[Daphne’s Lamp](#)  
[Defeat MSA](#) - Multiple System Atrophy  
[Dempster Family Foundation](#) – 22q11.2 deletion, DiGeorge Syndrome, VCFS  
[DPHS Foundation](#)  
[DNA Checkup](#) – Recessive Genetic Disorders  
[Donors Cure](#)  
[Dravet Syndrome Foundation](#) – Dravet Syndrome  
[Drépanovie- Association des Drépanocytaires de Côte D'Ivoire](#) - Sickle Cell Anemia  
[Dup15q Alliance](#) – Chromosome 15q Duplication Syndrome  
[DYRK1A Community](#) – DYRK1A  
[Dyskeratosis Congenita Outreach](#) – Dyskeratosis Congenita  
[Dystonia Medical Research Foundation](#) – Dystonia  
[EB Research Partnership](#) – Dystrophic Epidermolysis Bullosa  
[EDMD International, Inc.](#) – Emery-Dreifuss Muscular Dystrophy  
[EDSers United](#) – Ehlers Danlos Syndrome  
[Ehlers-Danlos Network CARES Foundation](#) – Ehlers Danlos Syndrome  
[Ehlers-Danlos Support Group of Greater Kansas City](#) – Ehlers Danlos Syndrome  
[Endosalpingiosis Foundation Inc](#)– Endosalpingiosis  
[Emily’s Entourage](#) – Cystic Fibrosis  
[Epidermoid Brain Tumor Society](#) – Epidermoid brain tumor  
[Epilepsy Warriors Foundation](#) – Epilepsy  
[Erdheim-Chester Disease Global Alliance](#) – Erdheim-Chester Diseases  
[Ethan Lindberg Foundation](#) – Congenital Heart Disease  
[Ethan’s Reason](#) – Batten Disease

[EveryLife Foundation](#) – Multiple Rare Diseases

[Fabry Australia](#) – Fabry Disease

[Fabry Support and Information Group](#) – Fabry Disease

[Familial Adenomatous Polyposis Foundation](#) – Familial Adenomatous Polyposis

[FamilieSCN2a Foundation](#) – SCN2a gene mutations

[FCS Foundation](#) – Familial Chylomicronemia Syndrome

[Feeding Tube Awareness Foundation](#) – Multiple Rare Diseases

[FH Foundation](#) – Familial Hypercholesterolemia

[Fibromadness](#)– Fibromyalgia

[Fibromuscular Dysplasia Society of America](#) – Fibromuscular Dysplasia

[Fibrous Dysplasia Foundation](#) – McCune Albright syndrome, Fibrous dysplasia

[Fighting H.A.R.D. Foundation](#) – Rare Disease, Chronic Illness

[Findacure](#) – Multiple Rare Diseases

[FIRST](#) – Ichthyosis Skin Disease

[FMD Chat](#) – Fibromuscular dysplasia

[FMF & AID Global Association](#) – Familial Mediterranean Fever & Autoinflammatory Diseases

[FIRST: Foundation for Ichthyosis & Related Skin Types](#) – Skin Diseases, Ichthyosis

[Foundation for Angelman Syndrome Therapeutics](#) – Angelman Syndrome

[Foundation for Batten Hope](#) – Batten Hope

[Foundation for Mitochondrial Medicine](#)– Mitochondrial and Related Diseases

[Foundation for Prader-Willi Research](#) – Prader-Willi Syndrome, abnormal chromosome 15 (15q11-q13).

[Foundation for Sarcoidosis Research](#) – Sarcoidosis

[FPIES Foundation](#) – Food Protein-Induced Enterocolitis Syndrome

[Friedreich’s Ataxia Research Alliance](#) – Friedreichs Ataxia

[Fundación Red Sanfilippo](#) – Sanfilippo Syndrome / MPS III

[Garrett the Grand](#) – Batten Disease

[Gaucher Association of Australia & New Zealand](#) - Gaucher

[GBS/CIDP Foundation International](#) – Guillain-Barré Syndrome, Chronic Inflammatory Demyelinating Polyneuropathy

[Gene Giraffe Project](#) – Multiple Rare Diseases



[Genetic Alliance UK](#) – Multiple Rare Diseases

[Global Hydranencephaly Foundation](#) – Hydranencephaly

[GNE Myopathy International](#) – GNE Myopathy, Hereditary Inclusion Body Myopathy ,  
HIBM

[Grey's Gift Memorial Foundation](#) – Globoid Cell Leukodystrophy, Krabbe Disease,  
Newborn Screening

[GRIN2B Foundation](#)

[Grupo De Estudos Doencas Raras](#) –Multiple Rare Diseases, Brazil

[Guardian Hands Foundation](#)– Multiple Rare Diseases

[Gwendolyn Strong Foundation](#) – Spinal Muscular Atrophy

[Hadley Hope Fund](#) – Niemann-Pick Type C disease

[HAE Canada](#) – Hereditary Angioedema

[Hairy Cell Leukemia Foundation](#) - Hairy Cell Leukemia

[Hannah's Hope Fund](#) – Giant Axonal Neuropathy

[Harmony 4 Hope](#) – Multiple Rare Diseases

[Harry's Fund](#) – Cri du Chat syndrome

[HCU Network America](#)

[HD-Care](#) – Huntington's Disease

[Health Advocacy Summit](#)– Chronic Disease

[Help 4 HD International](#) – Huntington's disease

[Helping Hands for GAND, Inc.](#) – GATAD2B-associated neurodevelopmental disorder

[Hemophilia Foundation of Southern California](#)– Genetic Bleeding Disorders

[Hepatitis Foundation International](#) – Hepatitis

[Hereditary Angioedema Association](#) – Hereditary Angioedema

[Hereditary Hemorrhagic Telangiectasia Foundation International](#) – Hereditary  
Hemorrhagic Telangiectasia

Highway of Hope

[Histiocytosis Association](#) – Histiocytic Disorders, Langerhans Cell Histiocytosis

[Hope 4 Bridget Foundation](#) – Batten Disease

[Hope4tylerandluke](#)

[Hope for Javier](#) – Duchenne Muscular Dystrophy

[HOPE for SCD](#) – Sickle Cell Disease

[Hope for Trisomy 13 & 18](#) – Trisomy 13 & 18 and related disorders, Edwards and Patau Syndrome.

[Hope 4 Tyler and Luke](#) – Med 23 gene defect

[HPS Network](#) – Hermansky-Pudlak Syndrome

[HSAN1E Society](#) – Hereditary Sensory and Autonomic Neuropathy, Type 1E

[HudsonAlpha Institute for Biotechnology](#)

[Hunter Evan Short Gut Foundation](#) – Short Gut Syndrome

[Huntington's Disease Society of America, Inc.](#) – Huntington's Disease

[Huntington's Disease Youth Organization \(HDYO\)](#)

[Hydrocephalus Association](#) – Hydrocephalus

[HyperIGM Foundation](#) – Hyper IGM Syndrome

[Hypoparathyroidism Association](#) – Hypoparathyroidism

[iCAN Research](#) - Multiple Rare Diseases

[Idic15 Canada](#)– Chromosome 15q11.2-13.1 Duplication Syndrome

[I Have IIH Foundation](#) – Idiopathic Intracranial Hypertension

[IHope Foundation](#) – Intractable Hypertension

[Illinois Spina Bifida Association](#) - Spina Bifida

[Incontinentia Pigmenti International Foundation](#) – Incontinentia Pigmenti

[Intermountain PKU and Allied Disorders Association](#) – Phenylketonuria and allied disorders

[International Cystinuria Foundation](#) – Cystinuria

[International Essential Tremor Foundation](#) – Essential Tremor

[International Firefighter Cancer Foundation, Inc.](#) – Multiple Rare Cancers

[International FOP Association](#) – Fibrodysplasia Ossificans Progressiva, Myositis Ossificans Progressiva

[International Foundation for Autoimmune and Autoinflammatory Arthritis](#)

[International Foundation for CDKL5 Research](#)

[International FOXG1 Foundation](#) – FOXG1 gene mutation

[International Pemphigus & Pemphigoid Foundation](#) – Pemphigus, Pemphigoid

[International WAGR Syndrome Association](#) – WAGR Syndrome, 11p Deletion Syndrome

[ISMRD The International Advocate for Glycoprotein Storage Diseases](#) – Glycogen Storage Disease

[Jamie's Dream Team](#) – Multiple Rare Diseases

[Jansen's Foundation](#) – Jansen's Disease

[Jett Foundation](#) – Duchenne Muscular Dystrophy

[Jonah's Just Begun](#) – Sanfilippo Syndrome, Mucopolysaccharidoses (MPSIII)

[Jonah's Just Begun- Foundation to Cure Sanfilippo](#)– Sanfilippo

[Joshua Frase Foundation](#) – Myotubular Myopathy

[Joshua Hellmann Foundation for Orphan Disease](#) – Multiple Rare Diseases, Hong Kong

[Joubert Syndrome & Related Disorders Foundation](#) – Joubert Syndrome

[Judson's Legacy](#) – Krabbe's Disease

[Julia and Maya Clark Foundation](#)– Mitochondrial disorders and CDKL5

[Kabuki Syndrome USA](#) –Kabuki syndrome

[KCNQ2 Cure](#) – KCNQ2

[KIF1A.org](#)

[Klippel-Feil Syndrome Alliance](#) – Klippel-Feil Syndrome

[Klippel-Feil Syndrome Freedom](#) – Klippel-Feil Syndrome

[Kneading Hope](#) – Multiple Rare Diseases

[KnowTheGlow](#) - Multiple Rare Diseases

[KrabbeConnect](#) – Krabbe

[K-T Support Group](#) – Klippel-Trenaunay Syndrome

[Kure for Kulas](#) – Spinal muscular atrophy (SMA)

[LAL Solace, Inc.](#) – Lysosomal Acid Lipase disease, LAL Deficiency, Wolman Disease

[Layla's Hope Foundation](#) – KCTD7 (Progressive Myoclonic Epilepsy Type 3)

[Lauren's Hope](#) – Hypomagnesemia with Secondary Hypocalcemia (HSH)

[Legg Calve Perthes Foundation](#) – Legg-Calve-Perthes Disease

[Leiomyosarcoma Direct Research Foundation](#) – Leiomyosarcoma

[LEMS Patients](#) – Lambert-Eaton Myasthenic Syndrome

[LGS Foundation](#) – Lennox-Gastaut Syndrome

[LHON Project](#) – Leber Hereditary Optic Neuropathy

[Li-Fraumeni Syndrome Association](#)– Li-Fraumeni Syndrome

[Lipodystrophy United](#) – Lipodystrophy

[Lipoprotein\(a\) Foundation](#) – High Lipoprotein(a)

[Little Hercules Foundation](#) – Duchenne Muscular Dystrophy

[Little Miss Hannah Foundation](#) – Multiple Pediatric Rare Diseases

[Littlest Tumor Foundation](#) - Neurofibromatosis

[Live4TheCure](#) – All Rare Diseases

[Living LFS](#) – Li-Fraumeni Syndrome

[LouLou Foundation](#) – CDKL5 Deficiency Disorder

[Lowe Syndrome Association](#)– Lowe Syndrome

[LSD Society](#)– LSD, Pakistan

[Luka the Lion Foundation](#) – Multiple Pediatric Rare Diseases

[Lymphangiomatosis & Gorham’s Disease Alliance](#) – Lymphangiomatosis, Gorham’s Disease

[Lynch Syndrome International](#) – Lynch Syndrome

[Lysosomal Diseases New Zealand](#)

[Lysosomal Storage Disorders Support Society](#)– Lysosomal Diseases, India

[M-CM Network](#) – Macrocephaly-capillary malformation

[Mackenzie’s Mission](#) - Amyloidosis

[Marrow For Life, Inc.](#) – Stem Cell Treatments for Rare Diseases

[Mason Shaffer Foundation](#) – Malignant Infantile Osteopetrosis

[Massachusetts Biotechnology Council](#) – Multiple Rare Diseases

[MEPAN.org](#) – MEPAN Syndrome

[Metaplastic Breast Cancer Global Alliance](#)

[Meningitis Foundation of America](#)

[MHE Coalition](#) – Multiple Hereditary Exostoses, Multiple Osteochondromatosis, Hereditary Multiple Exostoses

[Milo’s Journey Foundation](#) – Undiagnosed

[Minutes Matter](#) – Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)

[Miracle Flights](#) – All Rare Diseases

[Miracle For Madison & Friends](#) – Spinal Muscular Atrophy

[Mission: Cure](#)

[Mission Massimo Foundation](#) – Leukodystrophy

[Mitchell Thorp Foundation](#)– Multiple Rare Diseases

[MitoAction](#) – Mitochondrial Disease

[MLD Foundation](#) – Metachromatic Leukodystrophy

[Moebius Syndrome Foundation](#) – China Doll Syndrome, Moebius Syndrome

[Mommies of Miracles](#) – Multiple Pediatric Rare Diseases

[Mo Songs for Kerry](#)– Li Fraumeni Syndrome

[MSA-AMS and World MSA Day](#)

[MSA NJ](#)– Multiple System Atrophy

[MSUD Family Support Group](#)

[MTM-CNM Family Connection, Inc.](#) – Myotubular and Centronuclear Myopathy

[Muscular Dystrophy Society Kenya](#) – Muscular Dystrophy

[Myasthenia Gravis Hope Foundation](#)– Myasthenia Gravis

[Myositis Support and Understanding Association](#) - Idiopathic Inflammatory Myopathies, Myositis

[Myotonic Dystrophy Foundation](#) – Myotonic Dystrophy

[Myrovlytis Trust](#) – Birt Hogg Dube Syndrome

[Narcolepsy Network](#) – Narcolepsy

[National Ataxia Foundation](#) - Ataxia

[National Foundation for Ectodermal Dysplasias](#) – Ectodermal Dysplasias

[National Gaucher Foundation](#) – Gaucher Disease

[National LeioMyoSarcoma Foundation](#) – LeioMyoSarcoma

[National Lymphedema Network](#) – Lymphedema-distichiasis syndrome, Hereditary lymphedema type II & other lymphademas

[National Marfan Foundation](#) – Marfan Syndrome

[National MPS Society](#) – Mucopolysaccharidoses

[National Niemann-Pick Disease Foundation](#) – Niemann Pick Disease

[National PKU Alliance](#) – Phenylketonuria

[National PKU News](#) – Phenylketonuria

[National Spasmodic Dysphonia Association](#) – Spasmodic Dysphonia, Laryngeal Dystonia

[National Stem Cell Foundation](#)

[National Tay-Sachs & Allied Disease Association](#) – Tay-Sachs, Canavan, Sandhoff, GM1 & related diseases

[NBIA Disorders Association](#) – Aceruloplasminemia, Neurodegeneration w/ Brain Iron Accumulation disorders, Hallervorden-Spatz Syndrome

[NEHI Research Foundation](#) – Neuroendocrine cell hyperplasia of infancy

[Neurofibromatosis Network](#) – Neurofibromatosis Disease

[Neuromuscular Disease Foundation](#) – Neuromuscular Disease

[Nevus Outreach, Inc.](#) – Congenital Melanocytic Nevi and Related Disorders

[Newborn Coalition Foundation](#) – Newborn Screening

[New Zealand Organisation for Rare Disorders](#) – Multiple Rare Diseases

[New Zealand Pompe Network](#)

[Next Step Fund](#) – Life Threatening Diseases

[NF2BioSolutions](#) – Neurofibromatosis Type 2

[NGLY1 Foundation](#) – NGLY1 deficiency, N-glycanase deficiency

[Nicholas Volker One In A Billion Foundation](#)

[Niemann Pick Research Foundation](#) – Neimann Pick Disease

[Noah’s Hope](#) – Batten Disease

[Nontuberculous Mycobacteria Info & Research](#) – Pulmonary Nontuberculous Mycobacterial

[Noonan Syndrome Foundation](#) – Noonan Syndrome

Noonan Syndrome Support Network – Noonan Syndrome

[NR2F1 Foundation](#) - Bosch Boonstra Schaaf optic atrophy syndrome

[NUBPL Foundation](#)

[Organic Acidemia Association](#) – Organic Acidemia

[Organization for Rare Diseases India](#) – Multiple Rare Diseases

[Orphan Disease Center](#)– Multiple Rare Diseases

[Osteopetrosis Society](#) – Osteopetrosis

[Oxalosis and Hyperoxaluria Foundation](#) – Hyperoxaluria, Oxalosis

[Pachyonychia Congenita Project](#) – Pachyonychia Congenita

[PANDAS Network.org](#) – Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

Parent/Consumer Advocate for MS

[Parent Project Muscular Dystrophy](#) – Duchenne Muscular Dystrophy, Becker Muscular Dystrophy

[Pathways for Rare and Orphan Studies](#) (PROS) – Multiple Rare Diseases

[PBCers Organization](#)

[PCDH19 Alliance](#) – PCDH19 Epilepsy

[Pediatric Brain Foundation](#) – Pediatric Neurologic Disorders

[Pediatric Hydrocephalus Foundation](#) – Hydrocephalus

[Perthes Kids Foundation](#) – Legg-Calvé-Perthes Disease

[Phelan-McDermid Syndrome Foundation](#) – 22Q13 Deletion Syndrome, Phelan-McDermid Syndrome

[Pheo Para Alliance](#) – Pheochromocytoma & Paraganglioma Diseases

[Pheo Para Project](#) – Pheochromocytoma & Paraganglioma

[Pitt Hopkins Research Foundation](#) – Pitt Hopkins

[Pituitary Network Association](#) – Pituitary Disorders

[PKD Foundation](#) – Polycystic Kidney Disease

[PKS Kids](#) – Pallister-Killian Syndrome

[PKS Kids Italia Onlus](#) – Pallister-Killian Syndrome

[Platelet Disorder Support Association](#) – Immune Thrombocytopenia

[PMG Awareness Organization, Inc.](#) – Polymicrogyria

[Pompe Foundation, India](#) – Pompe Disease

[Potocki-Lupski Syndrome Outreach Foundation, Inc](#) – Potocki-Lupski Syndrome

[Prader-Willi California Foundation](#) – Prader-Willi Syndrome

[Prader-Willi Syndrome Association](#) – Prader-Willi Syndrome

[PRISMS, Inc.](#) – Smith-Magenis Syndrome

[Project 8P](#) – Chromosome 8p

[Progeria Research Foundation](#) – Hutchinson-Gifford Progeria Syndrome

[Progressive Familial Intrahepatic Cholestasis Advocacy and Resource Network, Inc.](#) – Progressive Familial Intrahepatic Cholestasis

[PRP Alliance](#) – Pityriasis Rubra Pilaris

[PSC Community](#) – Primary Sclerosing Cholangitis

[PSC Partners](#) - Primary Sclerosing Cholangitis

[PTEN Hamartoma Tumor Syndrome Foundation](#)

[PTen World](#) – Cowden’s Syndrome

[Pulmonary Hypertension Association](#) – Pulmonary Hypertension

[PURA Syndrome Foundation](#) – PURA Syndrome

[Putting Rare Diseases Patients First!](#) - All Rare Diseases

[PVNH Support and Awareness](#) – Periventricular Nodular Heterotopia

[RACC- UK](#) – Periodic Fever Syndromes

[RareKC](#) – All Rare Diseases

[Rare & Undiagnosed Network](#) – Multiple Rare Diseases, Undiagnosed

[Rare Disease Foundation](#) – Multiple Rare Diseases, Canada

[Rare Disease Ghana Initiative](#)– Multiple Rare Diseases, Ghana

[Rare Disease Kenya](#) – Multiple Rare Diseases, Kenya

[Rare Disease UK](#) – Multiple Rare Diseases

[Rare Disease United Foundation](#) – Multiple Rare Diseases

[Rare Genomics Institute](#) – Multiple Rare Diseases

[Rare New England](#) – Multiple Rare Diseases

[Rare Science](#) – Multiple Rare Diseases

[Rare Support](#) –

Rare United Network

[Raríssimas – Associação Nacional de Deficiências Mentais e Raras](#) – Multiple Rare Diseases, Portugal

[RASopathies Network USA](#) – RASopathy Syndromes

[RecurrentMeningitis Association](#) – Recurrent Meningitis

[Reflex Sympathetic Dystrophy Syndrome Association \(RSDSA\)](#) – Complex Regional Pain Syndrome

[Relapsing Polychondritis Awareness and Support Foundation](#) – Relapsing Polychondritis

[Remember the Girls](#) – X-linked Recessive Diseases

[Rettsyndrome.org](#) – Rett Syndrome

[Rhode Island Ehlers Danlos Syndrome Awareness and Support Group](#)– Ehlers Danlos Syndrome

[Ring 14 USA](#) – Chromosome 14 disorders

[Russell-Silver Support Network](#) – Russell-Silver Syndrome, Small Gestational Age

[Ryan Wersten MIOP Foundation](#) – Malignant Infantile Osteopetrosis

[Salla Treatment and Research Foundation](#) – Salla Disease

[Sanfilippo Children’s Foundation](#) – SanFilippo

[Sanfilippo Foundation for Children](#) – SanFilippo

[Sanford Research](#) – Multiple Rare Diseases



[Sarcoidosis of Long Island](#) – Neurosarcoidosis, Sarcoidosis

[Sarcoma Foundation of America](#) – Sarcoma

[SATB2 Gene Foundation](#)– SATB2 Associated Syndrome

[Saving Case and Friends](#) – Hunter Syndrome, Mucopolysaccharidosis/MPS II

[SBS Cure Project](#) – Short Bowel Syndrome/Intestinal Failure

[SCAD Alliance](#) – Spontaneous Coronary Artery Dissection

[SCN2A Australia](#) - SCN2A

[SETBP1 Society](#) – SETBP1

[Shwachman-Diamond Syndrome Foundation](#) – Shwachman Diamond Syndrome

[Sickle Cell 101](#) – Sickle Cell Disease

[Sickle Cell Consortium](#) – Sickle Cell Disease

[SLC6A1 Connect](#) – SLC6A1 (GAT1)

[Smith-Kingsmore Syndrome](#) – Smith-Kingsmore Syndrome

[SMS Research Foundation](#) – Smith-Magenis Syndrome

[Snappin' Ministries](#) – Multiple Rare Diseases

[Sofia Sees Hope, Inc.](#)

[Soft Bones Inc.](#) – Hypophosphatasia

[Soft Bones Canada](#) – Hypophosphatasia

[Spinal CSF Leak Foundation](#) – Cerebrospinal Fluid

[SSADH Association](#)– Succinic Semialdehyde Dehydrogenase Deficiency

[Step by Stone Association](#)– Multiple Rare Diseases, Kenya

[Stop ALD Foundation](#) – X-linked adrenoleukodystrophy

[STXBP1 Disorders/Foundation](#)

[Super Kids: Mission Zero Inc.](#) – Epilepsy

[Super T's Mast Cell Foundation](#)–Mast Cell Activation Disorder

[Supporters of Families with Sickle Cell Disease, Inc.](#) – Sickle Cell Disease

[Supporting Families with Koolen-deVries Syndrome](#) – Koolen – deVries Syndrome, C17q21.31 microdeletion syndrome

[Support Organization for Trisomy 18, 13 & Related Diseases](#) – Trisomy 13 Disorder, Trisomy 18

[Sweet Nectar Society](#) – Multiple Rare Diseases

[Syndromes Without A Name USA](#) – Undiagnosed

[Tango2 Research Foundation](#) - Tango2

[Taylor's Tale](#) - Batten Disease

[Team Impact](#)

[Team Jeffery for PF](#)

[Team Titin](#) - Titinopathies

[Teddington Trust](#) - Xeroderma Pigmentosum

[The 22q 11 Ireland support group](#) - 22q11.2 deletion syndrome

[The AADC Research Trust](#)- Aromatic Amino Acid Decarboxylase Deficiency (AADC)

[The APS Type 1 Foundation](#)- Autoimmune Polyglandular Syndrome Type 1

The Avery's Fight Foundation

[The Bow Foundation](#)- GNAO1

[The Brain Recovery Project](#) - Multiple Rare Diseases

[The Burning Limb Foundation](#)

[The Calliope Joy Foundation](#)- Leukodystrophy

[The CHARGE Syndrome Foundation](#)- CHARGE Syndrome

[The Charles E. Holman Morgellons Disease Foundation](#)- Morgellons Disease

[The Chromosome 18 Registry & Research Society](#) - Chromosome 18 disorders

[The Cilly Cell Project](#) - Sickle Cell Disease

[The Coalition Against Pediatric Pain](#) - Multiple Pediatric Rare Diseases

[The Conley Cushing's Disease Fund](#) - Cushing's Disease

[The COPD Foundation](#) - Chronic Obstructive Pulmonary Disease

[The Cure Tay-Sachs Foundation](#)

[The Cute Syndrome](#) - PCDH19 Epilepsy and SCN8A Epilepsy

[The Double Hit Lymphoma Foundation](#) - Double Hit Lymphoma

[The FAVA Foundation](#) - Fibro Adipose Vascular Anomaly

[The Global Foundation for Peroxisomal Disorders](#) -Peroxisome Biogenesis Disorder, Zellweger Spectrum Disorder

[The Hypersomnia Foundation](#)- Idiopathic Hypersomnia

[The Jansen's Foundation](#)- Jansen Type Metaphyseal Chondrodysplasia

[The LAMFoundation](#) - Lymphangi leiomyomatosis (LAM)

[The Life Raft Group](#) - Gastrointestinal Stromal Tumor (GIST)

[The Marfan Foundation](#) - Marfan Syndrome

[The Mastocytosis Society Inc](#) – Mastocytosis and Mast Cell Activation Disease

[The Mastocytosis Society Inc Southern California Support Group](#)

[The Metabolic Foundation](#) – Metabolic Disorders

[The Morgan Leary Vaughan Fund](#)

[The Mowat-Wilson Syndrome Foundation](#) – Mowat-Wilson Syndrome Foundation

[The Myositis Association](#) – Myositis

[The National Gaucher Foundation of Canada](#) – Gaucher Disease

[The NICER Foundation](#) – Narcolepsy

[The Network of Tyrosinemia Advocates](#) – Tyrosinemia

[The Rare Genomes Project at the Broad Institute of MIT and Harvard](#) – Multiple Rare Diseases

[The Snyder-Robinson Foundation](#) – Snyder-Robinson Syndrome

[The Speak Foundation](#) – Neuromuscular Diseases

[The Sturge-Weber Foundation](#) – Sturge-Weber Syndrome

[The TBCK Foundation](#) - TBCK

[The TESS Foundation](#) – SLC13A5

[The Ultra Rare Disease Disorders and Disabilities Foundation](#) – Multiple Rare Diseases

[The Vision of Children Foundation](#) – Genetic Vision Disorders

[The WeHeal Foundation](#) - All Rare Diseases

[The Wiedemann-Steiner Syndrome Foundation](#) – Weidemann-Steiner Syndrome

[ThinkGenetic Foundation](#) – Multiple Rare Diseases

[Thisbe and Noah Scott Foundation, Inc.](#) – Pediatric Neurologic Disorders

[Timothy Syndromes Alliance](#) – Timothy Syndrome and CACNA1c mutations

[Translational Genomics Research Institute](#) – Multiple Rare Diseases

[Translational Pulmonary and Immunology Research Center](#) – Multiple Rare Diseases

[Traveling Awareness Bears](#) – Multiple Rare Diseases

[Trisomy 18 Foundation](#) – Trisomy 18, Edwards Syndrome

[TUBB3 Foundation](#) – TUBB3 Gene Mutations

[Tuberous Sclerosis Alliance](#) – Tuberous Sclerosis

[Tuberous Sclerosis Australia](#)

[Turner Syndrome Global Alliance](#) – Turner Syndrome

[Turner Syndrome Society of the United States](#) – Turner Syndrome

[U.R. Our Hope](#) – Undiagnosed

[United Leukodystrophy Foundation](#) – Leukodystrophies

[United Mitochondrial Disease Foundation](#) – Mitochondrial Encephalomyopathy

[Unique - Rare Chromosome Disorder Support Group](#) - Rare Chromosome and Single Gene Disorders

[Usher 1F Collaborative, Inc](#) – Usher Syndrome Type 1F

[Usher Syndrome Coalition](#) – Usher Syndrome

[USP7 Families](#) – USP7 Related Diseases

[Utah Rare](#)– Multiple Rare Diseases

[Vancouver Acromegaly Support Group](#) – Gigantism, Acromegaly

[Vincent Gaynor & Sophia's Cure Foundation](#) – Spinal Muscular Atrophy

[VWM Families Foundation, Inc](#) – Vanishing White Matter Disease VWM/CACH

[Wake Up Narcolepsy](#) – Narcolepsy

[White Sutton Syndrome Foundation](#) – White Sutton Syndrome (WHSUS)

[Wilhelm Foundation](#) – Undiagnosed

[William E Proudford Sickle Cell Fund](#) – Sickle Cell Disease

[Williams Syndrome Association](#)– Williams Syndrome

[Williams Syndrome Changing Lives Foundation](#) – Williams syndrome

[Williams Syndrome Family of Hope](#) – Williams syndrome

[Wiskott Aldrich Foundation](#) – Wiskott-Aldrich Syndrome

[Wobbly Feet Foundation](#) – Ataxia-Telangiectasia

[Wylder Nation](#) – Lysosomal Diseases

[XLH Network](#) – X-Linked Hypophosphatemia

[XP Family Support Group](#) – Xeroderma Pigmentosum

[Zoe's Story](#) – CRMO/CNO